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## INTRODUCTION

Improving pain control for patients with metastatic breast cancer will significantly reduce the morbidity of this disease. It is estimated that 185,700 women are newly diagnosed with breast cancer in the US each year (Parker et al., 1996). Approximately 70% of these women are diagnosed in the early stages of the disease, due mainly to progress in screening and diagnosis. Despite improvements in cancer care for patients with early stage disease, a large number of patients will still develop metastatic disease, and mortality rates for these patients remain relatively constant. Minority women are more likely than white women to have advanced disease at diagnosis, and treatment outcomes are worse for minority women (Freeman & Wasfie, 1989). Improving the quality of life of patients who will die of their disease, especially controlling their pain, should be as much a priority for these patients as improving the therapeutic approaches for their disease.

Women with metastatic breast cancer, especially those from minority populations, are not receiving optimum pain control. While it is estimated that pain could be well controlled in over 90% of patients with cancer (Foley, 1985), data from a recent national study indicate that 43% of women with metastatic breast cancer and pain are not adequately treated by the standards of the World Health Organization (Cleeland et al., 1994). Compared with other patients who have pain due to metastatic disease, women are more likely to be undertreated, and patients from sites treating primarily African American or Hispanic patients are three times as likely to receive inadequate analgesics. Minority patients recognize that they are undertreated; they more frequently report that they need more medication for pain, that they have less pain relief from pain treatment and shorter duration of pain relief from their medications. They also report more pain-related impairment of function.

Poor cancer pain control is a function of many factors, including those related to the inadequate pain management given by health care professionals and those related to barriers created by the health care system in general. Patient concerns, expectations, and behaviors also contribute to poor pain management (Cleeland, 1984; Ward et al., 1993). These patient-related factors include the belief that pain is inevitable, fears of addiction to analgesics, fears of building tolerance to analgesics, and fear of reporting pain to providers.

This project is developing patient educational materials, both video and written, for African American women and women of Hispanic descent. The project began with studies designed to establish the specific educational needs of women of each ethnic heritage. In consultation with medical experts of both African American and Hispanic descent, a video script was written that covered the perceived barriers to good pain control in both groups. This script is being reviewed by separate focus groups of women with cancer and pain from each group to determine the best presentation style for the educational material. Specific educational material developed for each group, African American and Hispanic, will be tested in a randomized clinical trial, entering women with breast cancer from each heritage group.

This project is based on the premise that patients who expect pain relief and are able to communicate their distress are liable to promote more responsive pain management from their health care providers. Identifying patient concerns and behaviors that limit effective pain management and providing gender and heritage-specific information and skills training to modify these concerns and

behaviors may present the most effective way, at least in the short term, to reduce the percentages of patients whose functioning is impaired by pain. Training for minority patients will need to be predicated on an assessment of the specific information and skills they will need to manage their pain.

## BODY

The program funded by this award assesses the needs of minority breast cancer outpatients for information and skills needed to manage pain. It then develops multi-media education and training materials that are linguistically and culturally appropriate for low socioeconomic status (SES) Hispanic and African American populations, and tests the effectiveness of these materials in a randomized clinical trial. To accomplish these tasks, we have (a) formed a network of three urban public hospitals that treat these patients, (b) established a multi-disciplinary team to meet project goals, and © activated three studies to assess the educational needs of this patient population. We will evaluate the effectiveness of the educational tools we develop in a randomized, controlled clinical trial for low SES African American and Hispanic outpatients with metastatic breast cancer and disease-related pain. If this program is effective, it can easily be introduced by other care centers where these patients are treated.

During the first year of this award the network of three urban hospitals was formed. These included University of Miami Hospitals and Clinics, Miami, FL; John Peter Smith Hospital, Fort Worth, TX; and Los Angeles County Medical Center, Los Angeles, CA. A research nurse was recruited at each site by each site investigator. The nurses are bilingual and each brings a special skill to this project. The nurses have backgrounds in community outreach, cancer research, and education for special populations. During the first three months of the project, the nurses completed several clinical exercises in order to develop skills and knowledge needed for this program: First, the nurses were trained in presenting questionnaires to the target populations and identifying the special assistance needs of the targeted population in filling out our forms and providing medical information. Next, the nurses evaluated the pain management programs within their institution by conducting pharmacy audits, chart audits, and patient observations. This allowed them to become familiar with the prescribing practices, chart information, and patients' clinic experiences for their specific institution.

In September of 1996, the Pain Research Group of the University of Wisconsin Medical School - Madison, the group responsible for the scientific and technical aspects of this project, relocated to the University of Texas - M D Anderson Cancer Center in Houston. Because of Department of Defense policy, the awarded home of the project remains at the University of Wisconsin. Prof. David DeMets will become project Principal Investigator when approved by the contracting agency. Also, in mid 1996, the Smith Hospital in Fort Worth radically changed its pattern of service due to the reassignment of Medicaid and other underserved patients to private hospitals, essentially eliminating the treatment of oncology patients seen there. The project subcontract with Smith hospital was terminated in November because of decreased accrual. Since re-establishing the project base at the UT MD Anderson Cancer Center (UTMDACC), we have recruited LBJ General Hospital here in Houston to serve as the third site for the project, with Vicente Valero, MD, Chief of Medical Oncology at LBJ Hospital as the principal site investigator. Dr. Valero is also on staff at UTMDACC as Assistant Professor of Breast Medical Oncology. Because of the relationship between UTMDACC and LBJ Hospital, no subcontract will be required to have LBJ participate as a project site.

To assess the needs of minority breast cancer patients, two descriptive studies (Study 001 and Study 002) have been completed that examine the environment in which these patients are treated and the type of treatment typically provided. A summary of these findings is included in this progress report. These studies provide an estimate of the quality of treatment at each of the sites prior to the introduction of the educational intervention. These studies will have to be completed at the LBJ hospital in order that these data can be used as a background to estimate the impact of the intervention there. The studies at LBJ are not necessary for the development of the intervention and should not delay the progress of the study. The development of the intervention has been guided by a third study: Structured interviews (Study 004) have been conducted with low SES African American and Hispanic women in Miami, Los Angeles and Fort Worth. Content analysis of these interview protocols is underway, and a summary of this content analysis on the first patients for whom coding has been completed is presented here.

The Principal Investigators and personnel, Site Investigators, and Research Nurses have met twice (November, 1995, and July, 1996) in this year of the project. The purpose of these meetings have been to review the protocols for the three needs assessment studies and to identify site problems or concerns with these studies. During the July meeting, project and site staff and the consultants on this project met to review the information from the structured interviews, to determine the optimal content of the video script from a behavioral and medical standpoint, and to develop a core video script (see Appendix 1) that would present essential information for both African American and Hispanic breast cancer patients. Prior to the final version of this script, each consultant read the full transcript of ten of the patient standardized interviews. One full transcription each of an African American and a Hispanic patient interview is presented as Appendices 2 and 3. The format and content of the written materials which will accompany the educational video were also discussed with the project consultants.

The production of the videos, scheduled for year 2, was delayed by purchasing requirements for the State of Wisconsin for outside vendors. These requirements mandated that the video producer specified in the contract and involved in the development of the project since its inception submit a new bid for the work specified in the contract. Moving the funding source to UTMDACC was determined to be the best way to produce the videos as specified in the project application we submitted. Video production has begun, and the African American video is targeted for completion early in 1997. Awaiting the input of the focus groups, video development is focused on recruiting actors and narrators from the target groups, and filming background hospital and home scenes.

Data management for the project has been transferred to the Community Oncology Program, UTMDACC, a program that is under the direction of Roger Winn, MD. This is the data management center for the MD Anderson NCI-funded CCOP research base, and the specific data management for this project will be under the direction of Joanne Bitsura, MPH, who has directed the data management for several NCI-sponsored clinical trials. Statistical analysis at UTMDACC will be supplemented with consultation by the Biostatistics Group at the University of Wisconsin-Madison.

While the videos are being produced, each site will pilot the study with fifteen minority cancer patients. The video and handbook will be those currently used in an Eastern Cooperative Oncology Group clinical trial (ECOG 3Z93) that also examines patient education for pain control. These materials, designed for majority patients, are not expected to be as effective as the tailored

materials produced by this project. However, utilizing them in the pilot study will allow for a run-in of the clinical trial, including patient identification and recruitment and data management and data transfer systems that the trial will employ. This pilot study will allow us to drop the run-in phase of the project with the targeted materials.

## **SUMMARY OF RESEARCH FINDINGS TO DATE:**

### **Study 001 - Outpatient Pain Needs Assessment Survey**

This study was done to obtain general descriptive data about pain, its severity and treatment, as well as general attitudes toward cancer pain treatment in African American and Hispanic patients with cancer and with pain. One aim of this study was to determine if pain relief, treatment, and patient-related barriers to cancer pain might differ between these two ethnic groups. Part of these data were collected as part of an Eastern Cooperative Oncology Group survey of minority patients. These data included 40 Hispanic and 22 African American women with breast cancer and pain. This project collected an additional 12 Hispanic and 7 African American breast cancer patients, for a total sample size of 52 Hispanic and 29 African American breast cancer patients with cancer-related pain.

This first study collected data on the pain of patients with recurrent or metastatic disease. The data included the patients' subjective report of pain and its impact on function (BPI), the perception of the treating physician concerning the patients' pain, and the details of the pain treatment these patients are receiving. The survey instruments are based on ones used by Cleeland and the Pain Research Group at the University of Wisconsin (Cleeland, 1986) and in the Eastern Cooperative Oncology Group. Patient and physician questionnaires for this study have been tested within the ECOG system (Cleeland et al., 1994). The patient form is an adaptation of the Brief Pain Inventory (BPI). The physician questionnaire was adapted from a similar survey that was administered to nurses. The survey was shortened and simplified. All changes were ones of form; no substantive changes were made. Forms for patients have been validated in culturally diverse groups and also in different language formats. The Spanish version, developed following a cross-translation method, has been validated in a multi-site study in Mexico and the Dominican Republic as part of a WHO demonstration project (Cleeland, 1989a). The Spanish version has also been successfully used in multi-center studies in the U.S. (Cleeland, et al, 1994). The simple pain and interference scales of the BPI are robust across different language and cultural groups (Cleeland, 1988; Serlin et al., 1995).

Physicians completed the "Physician Pain Assessment" survey form for each scheduled patient within 48 hours of the scheduled patient visit. The physician had the patient record but did not refer to the patient's completed BPI answers, and each physician signed a statement to that effect.

*Results:* There were no differences between the Hispanic and African American women in age or performance status. There was also no difference between the mean "worst pain" score for Hispanics (6.8 on a 0 to 10 scale) and African Americans (6.3). These data suggest that the groups were comparable in terms of demographics, disease status and pain severity. Adequacy of treatment was estimated by using the Pain Management Index (Cleeland, et al, 1994), a measure of whether or not patients were prescribed analgesics appropriate to the severity of their pain. The Index is based on the World Health Organization's recommendations for cancer pain management, as adopted by the AHCPR Guideline for Cancer Pain Management (Jacox, et al, 1994). As has been found in other studies, the majority of these minority woman were receiving analgesics of insufficient strength to manage their pain, although there was no heritage-based difference, with 66% of Hispanics and 64% of African Americans being under medicated with analgesics.



Previous research has documented that inadequate assessment is a strong predictor of analgesic under medication. We compared the patient's report of pain severity and her physician's estimate of her pain severity. Physicians underestimated pain severity in both groups of patients, 77 percent of the time for Hispanic women and 62 percent of the time for African American women (not a significant difference).

Several questions were asked about the patient's concerns about pain treatment, their need for additional information about pain management, and their view of the pain treatment that they were receiving. Several differences were found between the Hispanic and African American women. Hispanic breast cancer patients were three times more likely to say they needed more information about pain management (72 vs. 50%). A majority of both groups reported that they needed stronger pain medications (62% and 55%), although Hispanic women were three times more likely to say they needed more of their current analgesic prescription (49% vs. 24%). Even for those with appropriate prescriptions, a majority of Hispanics (55%) and African Americans (58%) took their analgesics two times a day or less, and African Americans were three times more likely (75%) than Hispanics (48%) to take their analgesics only when necessary. There was no difference between the groups in the number of Hispanics (29%) and African Americans (18%) who worried that they might be taking too many medications, although Hispanics were three times more likely (42%) to be worried about analgesic side effects than were African Americans (19%).

The results of this initial study documented that the majority of both Hispanic and African American women with breast cancer and pain were under medicated with prescription analgesics, and that their physicians underestimated the severity of the pain that their patients were experiencing. Hispanic women more frequently reported that they needed information about their pain, were more worried about taking too much pain medication, and were more concerned about the negative side effects of analgesics. While a majority of both groups were estimated to be incompletely compliant with presumed analgesic instructions (taking analgesics less often than would be typically recommended), African American women were three times more likely than Hispanic women to report that they took their analgesics only when necessary.

### **Study 002 - Health Professionals' Attitudes Toward Cancer Pain Management**

Surveys of health professionals have identified barriers and provided insight into current pain management practice patterns. Since it has been documented that minority cancer patients are at a greater risk for under management of pain, a survey of health professionals who treat this population should help in designing interventions that target minority cancer patients. We have gathered data on cancer pain management practice from a sample of physicians, nurses, and pharmacists who treat minority cancer patients of low socioeconomic status (SES).

The information from this study was used to (a) identify barriers to pain management which need to be addressed in educational interventions for patients in these minority study sites, (b) document the current status of pain management at the three study sites, and c) documents the current pain management practice at the three study sites, providing information about health professionals' perception of the barriers to good pain management at the practice sites for the development of these educational materials. The specific objectives of this study were (a) to determine the knowledge of cancer pain and its treatment among physicians, nurses, and pharmacists

treating minority patients with cancer of low SES at three sites, (b) to determine the methods of pain control being utilized at these three sites, (c) to determine the staff's perception of barriers to pain management at these three sites, and (d) to compare the knowledge and attitudes of staff at these three sites with the results of cancer pain treatment as reported by patients in the "Outpatient Needs Assessment Survey."

A shortened, booklet form of the Physician Cancer Pain Questionnaire developed by Charles S. Cleeland and the Pain Research Group at the University of Wisconsin was utilized (Cleeland et al., 1986). This questionnaire was the instrument used in a recent study of physicians in the Eastern Cooperative Oncology Group (VonRoenn et al., 1993). The questionnaire was designed to assess physicians' estimates of the magnitude of pain as a specific problem for cancer patients, physicians' attitudes about the adequacy of pain management for cancer pain, and their report of how they manage pain in their own practice setting. As a way of describing more specific pain management practice questions, they provided treatment recommendations for a patient presented in a scenario format. Information was also gathered on the physicians' practice setting, training, experience with caring for patients with cancer pain and personal experience with friends or family members with cancer, persistent pain or substance abuse. The shortened version of the survey takes about 10 minutes to complete.

*Eligibility:* The eligible participants included all physicians, nurses, and pharmacists serving minority patients of low SES with cancer at the following sites: John Peter Smith Hospital, Fort Worth, TX; University of Miami Hospital and Clinics, Miami, FL; Los Angeles County Hospital, Los Angeles, CA. Participants were excluded on the basis of sex, age, race, or educational preparation. No inducements were offered for participation in this study. Receipt of the completed questionnaire was considered informed consent.

*Methods:* Eligible staff members were identified by the Research Nurse at each site. All nurses, pharmacists, and physicians with some patient care responsibilities for oncology outpatients were approached. The Research Nurse at each site hand-delivered a copy of the survey form, cover letter, and postage-paid addressed return envelope to each eligible staff member. Participants returned completed surveys to the Pain Research Group via a postage-paid envelope. The surveys did not include the name of the respondent, nor were the identification numbers in any way connected with respondents' names in order to insure confidentiality. After three weeks site research nurses redistributed the surveys to the staff member who had not responded. Study data was identified by staff category and by institutional site but not by name of participant to insure anonymity and confidentiality.

*Accrual:* The second survey distribution for this study was completed at the last site in April, 1996. This study is now closed. We received a total of 49 questionnaires from the three sites: 14 from Fort Worth, 21 from Miami, and 14 from Los Angeles.

*Results:* A majority of the clinic staff respondents were female (66%) and Caucasian (63%). The remaining ethnic was 18% Asian, 15% African Americans and 4% others. Nurses were the largest group (54%) followed by physicians (38%) and pharmacists (8%).

Fifty-nine percent of respondents felt that their settings were doing a good or a very good job in managing pain, with 41% percent reporting only a fair, poor or very poor job. However, 77% said that patients receive adequate pain treatment in their setting. When asked about their professional background, about 21% reported poor training in cancer pain management.



The clinic staff were asked to rank potential barriers to optimal cancer pain management in his or her setting. The four top barriers were inadequate assessment of pain and pain relief (68%), inadequate staff knowledge of pain management (50%), patient reluctance to report pain (49%) and lack of staff time (41%).

To assess clinic staff pain management practice, a hypothetical case scenario was presented: *A 40 year old male cancer patient is hospitalized with severe untreated back pain of more than 1 month duration, attributable to bone metastases without vertebral collapse. He weighs 70 kg., has no cardiovascular or respiratory problems, and has a disease prognosis of more than 24 months. He has no history of medication allergies and is opiate naive. What would be your recommendation for initial pain management for this patient.*

Forty-one percent chose strong opioids (e.g. morphine, hydromorphone) appropriate for this level of pain, while 28% preferred mild opioids (e.g. codeine, vicodin) as their choice of drug. About 12% recommended NSAID's as the strongest analgesic to be used. Half would administer the drug around the clock while the other half would give it only as needed. Finally, respondents were asked: At what stage would you recommend maximum tolerated analgesic therapy for treatment of severe pain? Fifty percent of respondents would wait until the patient had less than six months to live before recommending maximum analgesia.

The responses from staff at these three project institutions can be compared with a previous study of the responses of oncologists from primarily non-minority clinics (VonRoenn, et al, 1993), and also with the recommendations of the Agency for Health Care Policy's Guidelines for the Management of Cancer Pain (Jacox, et al, 1994). In general, fewer of this group would use the more potent opioid analgesics and they would wait until the patient's disease is worse (prognosis of less than 6 months) before using maximum analgesia. Half of the respondents would prescribe analgesics on an as-needed basis rather than around the clock (as recommended by the AHCPR as well as the World Health Organization). As with the large oncologist sample, most saw poor assessment and poor staff knowledge as a major barrier to pain management, as well as patient reluctance to comply with taking medication. In contrast to the other group, health professionals in this sample from the three project hospitals felt that lack of time for pain treatment was a major barrier to pain management at their hospitals. Overall, there was a strong suggestion that the approach to the management of cancer pain at the three project sites was more conservative than the management of pain received by non-minority patients, suggesting an even more important need for the minority cancer patient to be more assertive in insisting on good pain relief. These data on professional attitudes also are in line with the finding of the first study in this project indicating that minority women with breast cancer are at greater risk for poorly-managed pain.

One purpose of this study was to estimate if there were any potential pain treatment biases at any of the hospitals that could possibly cause differences among the sites prior to the initiation of the intervention. We compared three items previously identified as being associated with pain treatment adequacy. These included the potency of the analgesic selected for the scenario patient, the stage of disease when professionals would use maximum analgesia, and the percentage of health professionals that would schedule analgesics around the clock. There were no differences among the hospital on any of these hospitals. It is also interesting to note that only about half of the clinicians at each of the three sites reported that their clinic was doing a good job or very good job

of relieving cancer pain. Minor differences were noted among the sites: For example, Ft. Worth but not the other two sites indicated that lack of equipment or skills was one of the three greatest barriers

#### **Study 004 - Perceived Pain Management Needs of Minority Outpatients**

We are examining African American and Hispanic breast cancer patient attitudes toward pain management and current pain management practice through the use of structured patient interviews. Structured interviews allow us to probe for previously unidentified barriers to pain management in these populations. In addition, tape-recorded interviews provide insight into the language style which may be appropriate for the target audience of the educational videos.

The current study is the final part of Phase 1 (needs assessment) in the development of educational materials for low SES African American and Hispanic patients. The information from this study is used to identify barriers to pain management which need to be addressed in educational interventions for patients. Results from the current study were used in conjunction with results from the Outpatient Needs Assessment Survey and the study of Health Professionals' Attitudes Toward Cancer Pain Management, described above, to determine the issues which need to be addressed in patient education materials designed to target African American and Hispanic cancer patients.

The primary objective of this study is to amplify our information about the perceived pain management needs of minority cancer patients of low SES. A second objective is to identify culturally specific language styles in order to ensure that educational materials will appropriately reflect language used by the target populations in discussing cancer pain.

*Eligibility:* Patients were recruited from the following participating sites: John Peter Smith Hospital, Fort Worth, TX; University of Miami Hospital and Clinics, Miami, FL; Los Angeles County Hospital, Los Angeles, CA. Patients must be outpatients seen in oncology/urology clinics at the participating institutions. Patients must have received a pathological diagnosis of cancer. Patients must have recurrent or metastatic disease. Patients must have chronic cancer pain. Patients must have had no surgery in the past 30 days. Patients must have a pain worst score on the Brief Pain Inventory (BPI) short form of  $>4$ . Patients must be  $\geq 18$  years of age. Patients must be a member of one of the following minority group categories: Hispanic, African American. Patients must have an ECOG Performance Status rating of 0,1,2, or 3. And patients must agree to participate.

*Methods:* This study was conducted at the outpatient clinics of the University of Miami, John Peter Smith Hospital and Los Angeles County Hospital. A private room was made available at each site for the structured interviews. Each institution should continue to recruit patients until ten African American patients and ten Hispanic patients have been accrued. Oncology outpatients who meet the eligibility requirements were asked to participate in the study. Reasons for nonparticipation were recorded on the Interview Recruitment Log.

The designated research nurse approaches all potentially eligible patients and administer the BPI short form (a standard, valid, and recommended questionnaire for the clinical assessment of cancer pain). If the patient's worst pain score is  $> 4$ , the nurse describes the purpose of the current study and ask the patient if he or she would like to participate.

If a patient agrees to participate, the nurse schedules a time for the interview, either on the same day or at a later time if that is more convenient for the patient. The research nurse gives the patient a consent form to read and sign before the interview. If the interview is scheduled for a later

date, the patient returns the signed consent form on the day of the interview. Patients are not to be registered until a signed consent form is obtained on the day of the interview.

On the day of the interview, the nurse registers the patient by faxing the registration form with the required information to the Pain Research Group. The Pain Research Group assigns a protocol sequence number to each patient registered and forwards a confirmation of registration, including the sequence number, to the institution.

The research nurse or a designated interviewer will conduct all interviews. Interviews were conducted in English or Spanish depending on patient preference. Interviews were tape recorded to be transcribed later. In addition, the interviewer take notes summarizing the response to each question. These interview summaries were used in the case of audio or interpretation difficulties during the transcription of the interviews.

On-Study Forms, BPI Short Forms, taped interviews and interview summaries, were forwarded to the Pain Research Group for tape transcription, data entry, coding, and analysis.

*Interview:* The structured interview has been developed by a committee including members of the Pain Research Group, site investigators, and consultants with extensive clinical experience with patients in each of the target groups. The interview was translated into Spanish and then back-translated by two separate bilingual translators. The interviews took 30 to 60 minutes to complete. Completed examples of both the English and Spanish versions are presented as Appendices 2 and 3.

*Pain Measure:* Pain and pain interference were measured with the Brief Pain Inventory (BPI) Short Form. The BPI asks patients to rate their pain for the last 24 hours on 0-10 scales at its "worst", "least", "average", and "now". The scales are presented on a 10 cm. line, with each number equidistant from the next. Each scale is bounded by the words "no pain" at the 0 end and "pain as bad as you can imagine" at the other. Using the same type of scales, patients are also asked to rate how their pain interferes with several quality of life domains including activity, walking, mood, sleep, work, and relations with others. These scales are bounded by "does not interfere" at the 0 end and "interferes completely" at the other. Patients are also asked to locate areas of pain on a human figure. Issues of the validity and reliability of the BPI have been examined in detail (Daut et al., 1983; Cleeland, 1989b; Serlin et al., 1995). English and Spanish revisions of the BPI have recently been used in a group wide ECOG study of cancer pain and its treatment, following a study of its patient acceptability and its feasibility as a clinical trials tool (Cleeland et al., 1994; Hatfield et al., 1991).

*Accrual:* As of January 1997, 20 female patients with metastatic or recurrent cancer have been registered in the study. The Fort Worth site has registered 1 patient; the Los Angeles site has registered 4 patients, and the Miami site has registered 15 subjects. Sixteen female patients (9 Hispanic, 7 African American) have completed the structured interview. Eleven of the patients have a diagnosis of metastatic breast cancer; the remaining 5 patients have other metastatic or recurrent cancers (lung, colon, lymphoma, myeloma). All of the patients have a pain worst score on the Brief Pain Inventory (BPI) short form greater than 4.

A content analysis of the completed interviews is in the preliminary stages. The results of the analysis are being used to identify the perceived pain management needs of minority women of low SES who have metastatic breast cancer. The identification of these needs are being used in the development of the educational materials for the clinical trial. Drafts of the video scripts and written

materials will be presented to focus groups of African American and Hispanic women who have a diagnosis of breast cancer. The preliminary analysis of the structured interviews (transcripts and audiotapes) also has identified characteristic phrases and other language styles that will be presented to the focus groups for review.

The preliminary content analysis compared the responses of the African American and Hispanic women to questions in four general areas relevant to pain management: information and communication about pain, treatment of pain, meaning of pain, and demographic data that might impact pain treatment. The preliminary analysis indicated that the responses of the eleven patients with breast cancer are comparable to those of the five patients with other types of metastatic or recurrent cancer. The pain-related concerns of the two subgroups of women do not appear to differ significantly.

In the information and communication area, the Hispanic and African American patients reported receiving information about cancer and cancer pain from multiple sources. Fourteen of the sixteen women interviewed reported that their physician is a primary source of information about cancer and cancer pain. A majority of the women also reported their physician as the most trusted source of information about cancer pain for themselves and their families. Eleven of the women reported using booklets as another important source of information. There were no differences between the African American and Hispanic women regarding their reliance on their physicians and written materials. Although several women commented that they would like to watch videos on cancer and cancer pain, they added that none were available to them. The Hispanic women were more likely than the African American women to use family members, friends, and/or other cancer patients as sources of information. Seven of nine Hispanic women mentioned these sources, as compared to three of the seven African American women.

When asked what kind of information received about cancer pain had been helpful, only 2 patients (one African American and one Hispanic) reported receiving helpful information about pain medications. Only one patient reported receiving helpful information about possible side effects of pain medication. A majority of the women in both ethnic groups stated that they have no difficulty talking about having cancer and cancer pain. Six of the seven African American women did report some difficulty talking about physical problems.

All of the patients stated that they talk to their physicians about their pain. Only five patients indicated that they discuss their pain with a nurse. Several patients commented that a nurse is rarely present in their clinic setting. The majority of patients in both ethnic groups feel that their physician understands about their pain. The Hispanic patients also emphasized that their family talks to them about their pain.

In the treatment area, all of the patients reported receiving medications prescribed by their physicians. A majority of the patients in both ethnic groups were receiving opioid medications. The Hispanic patients were more likely than the African American patients to report many concerns about becoming addicted to pain medicine. The Hispanic patients also reported that their family members were very concerned about the pain medicine. A majority of the Hispanic but not the African American women were worried about the efficacy of pain medicine. A majority of the patients in both ethnic groups reported concerns about being strong and not leaning on pain medicines. The overall assessment of attitudinal barriers to effective pain management suggested that the Hispanic patients have higher barriers than the African American patients.

The patients in both ethnic groups did not report major difficulty in obtaining their prescribed pain medications from a pharmacy. Prescriptions were typically filled and taken. Four of the nine Hispanic patients reported taking less of their pain medication than prescribed by their doctor. Only one patient in each ethnic group reported a problem with someone taking their pain medication from them. Gastrointestinal side effects from pain medications were commonly reported by both groups. Only one patient reported calling the cancer clinic about a side effect. Similarly, nearly all of the patients said that they would wait until their pain reached a 9 or 10 (on a 10-point scale) before calling the doctor, nurse, or clinic.

The African American and Hispanic patients described their pain in terms of sensations, associated emotions, and functional effects. The benefits of pain medications were described as feeling better, having a better mood, and being able to participate in work, family, and social activities. The demographic data indicate that the two ethnic groups are similar in terms of education, marital status, job status, and income. Most of the women are not married, have less than a high school education, and at least one child in the home. The average income is less than \$500 per month.

In sum, the results of the preliminary content analysis provide important information for the development of the educational materials. The patients in both ethnic groups appear to be dependent on their physicians for providing trustworthy information about cancer pain management. Thus, the video script includes physicians talking to their patients about cancer pain and available treatments. As Hispanic patients reported using family members, friends, and other cancer patients as important sources of information about cancer pain, it will be important to include these groups in the video and written materials.

The content analysis suggests that there is a need for helpful information about pain medications, possible side effects (especially gastrointestinal effects), and how to deal with side effects. The patients also need education about contacting their physician or nurse before their pain level is severe. The Hispanic patients and their families are very concerned about addiction to pain medication and demonstrate other attitudinal barriers to effective pain management. The patients in both groups can benefit from learning how to use pain rating scales to discuss their pain with health care providers.

The results of Study 004 provide valuable information for the development of the video scripts and written materials. Consistent with the results of Study 001, the majority of the patients interviewed were under medicated with prescription analgesics. There were no apparent differences between the African American and Hispanic women in this regard. A majority of patients in both ethnic groups reported noncompliance or incomplete compliance with presumed analgesic instructions. This finding also is consistent with the survey results from Study 001. The survey results indicated that Hispanic women were more worried about taking too much pain medication and were more concerned about the negative side effects of analgesics than the African American women. Similarly, the results of the structured interviews indicated that the Hispanic patients were more concerned about addiction and the efficacy of pain medicine than the African American patients.



## CONCLUSIONS

Preliminary analyses of the completed studies (outpatient pain needs assessment survey, health professionals attitudes toward cancer pain management and perceived pain management needs of minority outpatients) have provided us with key issues to consider in the development of the video and educational materials.

This project documents that the majority of Hispanic and African American women are not receiving analgesics of an appropriate strength for their pain, and that physicians underestimated pain severity in these minority breast cancer patients by as much as 77%. Improving patient-health care professional communication about pain should be associated with more appropriate analgesic prescription. Underestimation of pain severity can be due to any of the following: inadequate assessment of pain and pain relief, inadequate staff knowledge of pain management, patient reluctance to report pain and lack of staff time, all of which were reported by the health professionals as major barriers to pain management in our three project sites. Critical goals of the educational materials are to encourage patients to report pain and to give them the skills to report pain and the adequacy of their pain relief. Especially, the educational and video materials need to incorporate a method of addressing the reluctance of minority breast cancer patients to report pain and to do so before pain becomes very severe.

Both African Americans and Hispanics, as anticipated, need information about how to take analgesics (taking them around the clock instead of only when necessary) and side effect management. Both patient-based studies indicate that both groups of women report that they need more of this information, but few receive it.

Several of the concerns that our Hispanic and African American consultants thought would be important to include in the video and educational materials were not borne out by the assessment phase. For example, the results of the preliminary content analysis do not indicate major difficulties in obtaining prescribed analgesic medications. Also, although the investigators and consultants had speculated that financial, transportation, or other social problems might interfere with obtaining medications, few patients reported these types of barriers. Similarly, availability of the medications in the pharmacy was rarely mentioned. The patients also did not report problems with having analgesic medications stolen or taken away for reasons other than theft. Thus, the patient educational materials do not need to address these areas.

The studies also indicate that Hispanic and African American breast cancer patients have different educational needs. In addition to the obvious requirement for both English and Spanish versions of the materials, specific content will need differential emphasis. Hispanics may be much more concerned with becoming addicted to medication and worrying about using "too much." They also had more concerns about whether analgesics really relieve pain. work. Hispanics may benefit from having a greater emphasis on the family as involved in the pain treatment, with ways of reassuring family about the minimal risk of addiction to opioids used for pain control. African American breast cancer patients may tend to be more isolated in negotiating their pain treatment and will need special reinforcement for being their own advocates for pain relief. African Americans are also three times more likely to take their medications only when needed rather than as prescribed,

and the pharmacologic rationale for around-the-clock analgesics will need special emphasis in their educational material.

The results of the three studies do indicate that breast cancer patients feel a need for and can benefit from accurate information about analgesic medications and how to adhere to a regular medication schedule. Patients in both ethnic groups are concerned about possible side effects and need education about how to identify and cope with them. Data from all three studies demonstrate the need for patient education regarding patient-health care provider communication. Patients should be encouraged to discuss their pain with their doctors and nurses, to use pain rating scales, and to report major changes in pain level in a timely manner.

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# Managing Your Pain

draft three

page 1

Head and shoulders shot of  
Mrs. Jones

## Sound bite from Mrs. Jones:

It's kind of a dull ache that just got worse and worse.

Head and shoulders shot of  
Mrs. Manley

## Sound bite from Mrs Manley:

I couldn't get comfortable. I would just lie down and wait for it to pass.

Head and shoulders shot of  
Mrs. Johnson

## Sound bite from Mrs. Johnson:

Everything got on my nerves. Then I realized it was because I just didn't feel good.

Head and shoulders shot of  
Mrs. Williams

## Sound bite from Williams:

I was afraid to take the medicine. I didn't want to become a dope addict.

B-roll of patients in  
healthcare setting or in  
activities of daily life

## Narrator:

These cancer patients have all experienced some kind of cancer pain.. But instead of accepting pain as part of their disease, these patients are doing something about it.. You can, too.

B-roll of Mrs. Jones

## Sound bite from Mrs. Jones:

I told my doctor that the pain was bad and she gave me medicine that worked. Now I can do most of the things I used to do.

# Managing Your Pain

draft three

page 2

Head and shoulders shot of  
Mrs. Manley

B-roll of Mrs. Manley

B-roll continues

Title#1: YOU DON'T  
HAVE TO PUT UP WITH  
PAIN.

Head and shoulders shot of  
expert

Title#2: TELL YOUR  
DOCTOR OR NURSE  
ABOUT YOUR PAIN.

Doctor and patient in exam  
room

## Sound bite from Mrs Manley:

When the first medicine that the doctor gave me didn't help I told him about it and he gave me a new medicine that is working much better.

## Narrator:

Some patients believe that having pain is part of having cancer, but it's very important for you to know that you don't have to put up with pain. You have a right to pain relief.

## Dr. or other expert:

People who have cancer do not have to suffer. There are a lot of things that doctors can do to relieve the pain, but in order to help, the doctor and nurse need to know that you have pain.

## Narrator:

Even if your doctor or nurse don't ask, it's very important for you to tell them about your pain. Let's look at an example of how you can tell the doctor about your pain.

## Dr: (looking at chart)

Well, I hope things go well until we see you at your next appointment in about three weeks.

# Managing Your Pain

draft three

page 3

Close up of patient

**Patient:**

Um, Doctor, there's one other thing I wanted to ask you about. It's about the pain. It's gotten pretty bad. Sometimes I can barely get out of bed, it's so bad.

Close up of Doctor

**Dr. (writing in chart)**

uh, huh.

Close up of patient

**Patient:**

It's like a sharp stabbing pain in my back that just won't go away. I got this pamphlet from the nurse last time that says to give the pain a number, so I tried to think about it like that. And, uh, on a scale of zero to ten I'd say this pain is about a nine. I can't sleep. I don't feel like eating.

Close up of Doctor

**Dr. (paging through chart)**

Let's see. . . what are you doing for pain now ?

Close up of patient

**Patient:**

I'm taking Tylenol and resting. And the Tylenol helps some of the time. But other times it's not helping at all.

Two shot of Doctor and patient

# Managing Your Pain

draft three

page 4

Close up of Doctor

Reaction shot of patient

Freeze frame of exam room scene

Titles: repeat 1&2

DVE to replay of elements from previous scene

Show Scale

**Dr.:**

I'm going to give you something stronger than the Tylenol. And I want you to be sure to take it at the times I've written down for you. We can help you control this pain.

**Narrator:**

This patient took action to get pain relief. Let's look at exactly what she did. First, she told the Doctor that she had pain.

**Patient:**

Um, Doctor, there is one other thing I wanted to ask you about. It's about the pain. It's gotten pretty bad. Sometimes I can barely get out of bed, it's so bad.

**Narrator:**

Then, by rating the pain on a scale of zero to ten, she made it easier for her doctor to understand that this is not ordinary discomfort. Zero means no pain at all, 10 means pain as bad as it can get. A pain that is pretty strong might be a 5 or a 6 and a pain that is very hard to put up with might be an 8.

**Patient:**

Um, on a scale of zero to ten, I'd say this pain is about a nine.

# Managing Your Pain

draft three

page 5

Freeze frame

Title #3:  
BE CLEAR

DVE to replay

Freeze frame

DVE to replay

Freeze frame

DVE to replay

Freeze frame

**Narrator:**

She also described her pain in very clear terms. She didn't just say that she hurt. She described where she hurts and how the pain feels.

**Patient:**

It's like a sharp, stabbing pain in my back that just won't go away.

**Narrator:**

She also told the doctor that the pain is interfering with her life.

**Patient:**

I can't sleep. I don't feel like eating.

**Narrator:**

When the doctor asked what she is doing for the pain, she was ready.

**Patient:**

I'm taking Tylenol and resting. And the Tylenol helps some of the time. But other times it's not helping at all.

**Narrator:**

With this information, the doctor can make changes in the medicine to help with her pain.

# Managing Your Pain

draft three

page 6

DVE to

Close up of Doctor

**Dr.:**

I'm going to give you something stronger than the Tylenol. And I want you to be sure to take it at the times that I've written down for you. We can help you to control this pain.

Freeze frame  
Close up of patient

**Narrator:**

By being ready to tell her doctor about her pain in very clear terms, this patient got help.

Dissolve to B-roll of  
interview patients

Title #4: DON'T LET  
FEAR OF PAIN  
MEDICINES KEEP YOU  
FROM GETTING HELP.

But some people with cancer don't feel ok about asking for help. Patients sometimes let fear keep them from getting help. Let's look at some of the things that keep people from asking for pain relief.

Head and shoulder shot  
patient

**Patient or interview:**

My doctor gave me morphine, but I was afraid to take it. I see so many people taking dope. I don't want to be like them.

Head and shoulder shot of  
expert

**Dr. or other expert:**

Many people are afraid to take narcotics like morphine to help with their pain. But there are many reasons why you shouldn't worry about becoming addicted to these medicines.

B-roll of patient taking  
medicine

In fact, taking these medicines to control pain reduces the risk of addiction. Taking them at the regular times your doctor gives you will allow you to stay on top of the situation, keeping the pain under control.

# Managing Your Pain

draft three

page 7

Patient driving or in other  
activity of daily life.

B-roll of next patient

Head and shoulders shot of  
patient

Head and shoulders shot of  
expert

Patient in activities of daily  
life

**Patient:**

The pain got to where I just couldn't stand it, so I decided to give the morphine a try. It helps a lot. I don't feel high, I just don't feel the pain, so I can keep going about my business. It makes a big difference. I just wish I had realized that sooner.

**Narrator:**

Some patients want to save their pain medicine for times when the pain is severe. They are afraid the medication won't work if they take it at regular times.

**Patient or interview:**

I thought that if I took the medicine for mild pain, then when the pain got worse, it would not work as well. I thought that my body would get used to the pain medication, so that it wouldn't work if I need it later.

**Dr. or other expert:**

Don't hold back on pain medicines because you want to save them for more severe pain. You can and should get relief for the pain you have now. If the pain does get worse later, you can get relief from additional medicines or from different medicines. You can do the best job of controlling the pain by taking the medicine at the times the doctor has given you

**Patient or interview:**

After I started taking the pain medicine, my life got much more comfortable. I did have some constipation, but the doctor gave me something for that, too. Then, I could go back to the things I did before I got cancer.

# Managing Your Pain

draft three

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B-roll of next patient

**Narrator:**

Some patients are afraid of taking strong medicines because of things they have heard about the drug.

Head and shoulders shot of patient

**Patient or interview:**

I thought that getting morphine meant that I was dying. I thought that only people who are close to death were given morphine.

Head and shoulders shot of patient

**Dr. or expert:**

Morphine is not just for dying patients. In fact, morphine is one of our best medicines for controlling pain. By taking care of your pain, you can use your energy to fight the cancer---not the pain.

B-roll of patient in activities of daily life

**Patient or interview:**

After I started taking the morphine medicine, I was able to go back to work. I was practically pain-free. What a difference !

B-roll of next patient

**Narrator:**

Finally, some patients don't get help for their pain because they think that the doctor is too busy or doesn't want to know about pain.

Head and shoulders shot of patient

**Patient or interview:**

I thought that he didn't want to hear about my pain. He seemed very busy and I didn't want to bother him.



# Managing Your Pain

draft three

page 9

Head and shoulders of  
expert

B-roll of patient in activities  
of daily life

B-roll of other patients

Titles--

**1. YOU DON'T HAVE TO  
PUT UP WITH PAIN.**

**2. TALK TO YOUR  
DOCTOR OR NURSE**

**3. BE CLEAR**

## Dr. or expert:

Doctors and nurses who treat people with cancer need to know about your pain so that they can help you. Friends and family may not want to talk about pain because they feel helpless, but doctors are not helpless. If a medicine doesn't work, they'll find one that will. If you have side effects from one medicine, they can help you solve the problem. But they can only help if you tell them how you feel.

## Patient or interview:

I'm glad I mentioned the pain to my doctor because he made a change in my medicine that really helped. Now, he asks me about the pain on every visit.

## Narrator:

These patients made sure that they talked to their doctors about pain. And because of that, their pain got better. Let's review the important things you should do if you feel pain.

One, you should understand that you don't have to put up with pain just because you have cancer. Good pain control has to be part of your cancer treatment.

Two, talk to your doctor or nurse about the pain even if your doctor doesn't ask. If you don't tell them, they can't offer the help you need.

Three, be as clear as you can about where the pain is, how bad it is, what kind of pain it is, and how the pain affects your life.

# Managing Your Pain

draft three

page 10

Placing the pain on a scale of zero to ten can help the doctor understand how severe your pain is.

## 4. DON'T LET FEAR OF PAIN MEDICINES KEEP YOU FROM GETTING HELP.

Four, Don't let fears about pain medicines keep you from getting help.

## 5. DON'T GIVE UP

Five, and most important, DON'T GIVE UP. If the medicine you are taking doesn't help, keep telling the doctor about your pain until you get something that helps.

## STRUCTURED INTERVIEW

Pt. no. \_\_\_\_\_

TO THE PATIENT: I work with your doctor, and with the University of Wisconsin Pain Research Group. We are developing materials for cancer patients and their families to help them understand and take care of their cancer pain. In order to make the information easy-to-understand and meaningful, we are talking to several cancer patients, asking them to help us with our materials. I would like to talk with you about your experience of cancer and cancer pain. Your ideas will help us a great deal. This is not any kind of test. There are no right or wrong answers. Your thoughts and opinions are very important to us. Please let me know if you do not want to answer a question. All your answers will be kept confidential. Your doctor will not hear any of your answers and your answers will not affect your medical treatment in any way.

INFORMATION / COMMUNICATION

Okay, we're going to start now.

1. You have probably gotten different kinds of information about cancer and cancer pain. I am going to read a list of ways that people often get information about cancer.

From this list, could you tell me where you have gotten most of your information about cancer and cancer pain?

Was it from:

- Q. Talking to a doctor or nurse
- A. And from literature.
- Q. Well, did you get any of it from talking to a doctor or nurse?
- A. Mm hmm.
- Q. Yes, Okay.
- Q. Talking to family members
- A. No.
- Q. Talking to friends
- A. No.
- Q. Talking with a pastor, priest, or church members
- A. No.
- Q. Talking with members of a community group
- A. No.
- Q. Talking with persons who have or have had cancer, like in this clinic or...
- A. No. From my own experience.

Q. Reading booklets

A. Yes. I didn't read pamphlets this time because I've been through it before. \* They sent me a whole stack of pamphlets and tapes I haven't even listened to the tapes. Well you know because I've been through it before so you know, I didn't see no reason yet to go over the literature again.

Q. Alright

Q. Was it from watching videos

A. No.

Q. Watching TV shows

A. No.

Q. Watching commercials

A. Mm mm.

Q. Listening to radio shows

A. Mm mm.

Q. Did you get any information from any other source?

A. \* from my doctor and the nurse and the dietician when I had cancer before and my own personal experience.

Q. Okay. Okay.

2. Did you find any of this information that you got from them helpful?

A. Very helpful.

IF YES:

2a. Can you tell me what kind of information was most helpful and why it was helpful to you? Lets talk about now. The information you got from your doctor on the second round of cancer.

A. Well, only thing well they said to me is that I have cancer and that you know that you know I'm going to have to take chemo and radiation to reduce the tumor before I can get surgery this time. You know, and they don't know how things are going to go until you know after I go through chemo and radiation so they don't know what they going to have to do. But you know, that's all in general you know.

Q. Okay.

☆ 3. Have you talked about your cancer pain with members of your family, church or community group, or friends?

A. No. Right now the pain is beginning to pick up that's why you see you can tell I draw up.

- Q. Yeah, I can see it in your face.
4. What would be the best way or ways for you to get information about cancer pain?
- A. I guess through the literature, most of it \* came from the doctor, probably.
- Q. Okay.
5. What would be the best way for your family and those caring for you to get information about cancer pain?
- A. Well, I guess from me and from reading my literature and,
- Q. So literature,
- A. Yeah, I used to work at a hospital so I bought my own dietetic book and everything on food, food and diets and stuff like that so, I pretty much know how to take care of myself.
- Q. Alright, good, good.
6. Who do you trust the most to give you good information about cancer pain?
- A. Well, um, my doctor, you know, but has well haven't anybody really discussed it with me lately. I told them I been having some pain, when I first discussed it with Dr. \* she said it's probably because the the pain that was getting was the tumor growing extensively, but now it's beyond that so. And, I had to mention it to the doctor the other week when I was here you know all I got was antibiotics and he said that he couldn't give me anything so I told the lady again, when I you know I've been here since 7:00 and I told her again about how I was having really bad pains and it's getting hard to rest you know.
- Q. Which lady was that?
- A. The doctor I saw a while ago.
- Q. Okay, today.
7. Who is the first person you talk to about a physical problem? Like when you have a physical problem, who do you talk to first?
- A. To my-
- Q. When you, Like lets say with your breast when you first started having the problem again,
- A. Oh, who did I talk to? A social service person
- Q. A social service person.
- A. Yes
- Q. Okay.
- A. To try to get some help I went to her.
8. Okay. Can you tell me why you spoke to that person first?

- A. Well, it was I was having some more kind of problems and then it wound out you know, then I told her about the tumors in my breast so, you know she...
- Q. Responded.
- A. Responded, yes, by trying to help me get social security but not to the point to trying to help me see a doctor but like, I talked to a social service person in the Keys and she didn't tell me nothing but about we had a cancer treatment in Key West or nothing like that but they was moving a little slower now with the tumors was getting worse so I came to Jackson to try to get some help for myself starting in April.
- Q. Oh, okay.
- A. And so, that's how I wound up out of the county
- Q. How did you, when you came to Jackson, where did you go first?
- A. The emergency room.
- Q. Oh, so you went through the emergency room.
- A. Yes.
- Q. Okay.
9. Is it hard for you to talk about physical problems?
- A. No,
- Q. Okay
- A. Only when I'm in pain. Yeah.
- 9a. Okay, is it hard, well what makes it hard for you to talk about physical problems when your in pain?
- A. From the pain, I'm sitting I'm sitting up here you know, my toes drawn up I'm sucking in everything.
- Q. Yeah, I yeah okay.
10. Is it hard for you to talk about having cancer?
- A. No. I think it's because I've been through it before that 's why I can deal with it so easily right now, you know I haven't gotten afraid or I'm not scared or nothing. I guess maybe that won't come until after the treatments and after the after I know what the surgery gonna be. You know I'm trying not to get scared about it because I'm hoping that maybe I've gotten more years I'll survive the cancer this the second time around longer than I did the first time around so... you know.
- Q. Oh, okay.
11. Is it hard for you to talk about having cancer pain?
- A. Well, no. If you're hurting you're hurting.
- Q. Okay, alright.

12. Do you talk to your doctor or nurse about having cancer pain?

A. Yes, I've spoken to them

IF YES:

12 a. Which one? Both?

A. Yeah I've talked to Dr. \* at first, but you know, and then I talked to the male doctor when I first started coming to get the hemo checked up. And so you know he told me just continue to taking Tylenol and it's gone, it's gone beyond that.

Q. It's gone beyond that. And have you ever spoken to a nurse in the clinic here?

A. No. No more than, no only talk to a doctor, you know only the doctor been seeing me. They haven't had a nurse helping them or nothing like that so. And like I said the pain has gotten so worse, that's why I mentioned it to her again today. To a different doctor.

12b. Does the doctor ask you about having pain or do you usually have to tell them first?

A. I told her first that I was having the pain.

Q. Okay.

Q. When you talk to your doctor about the pain, does she or he ask about your pain, or do you bring the subject up first?

A. Well, I brought the subject up. If I didn't bring it up they wouldn't know. Because when I told her she said she'd speak to Dr. \* because she's the first doctor that treated me.

Q. Oh, okay, so that brought it to her attention.

A. Yes.

12c. What happened to you the last time you talked to a doctor or nurse about cancer pain? Did he or she understand your pain?

A. Well, she wasn't with me but a minute but I'm sure she did if she mentioned it to the doctor. Cause she mentioned it to Dr.

\*

Q. Okay.

IF YES: (12c) 1. What makes you feel he or she understood about your pain?

A. Because she said immediately that she would, you know, mention it and she left

the room and went to talk to the doctor.  
So I figured, she, you know.

Q. Okay.

13. Is there anyone else that talks to you about having pain?

A. No.

Q. No, okay.

14. What does the doctor or nurse tell you about treating your pain?

A. Well, like I said before, you know, when I first mentioned it he just told me to you know I told him I was taking Tylenol he just told me to keep taking Tylenol.

Q. Keep taking Tylenol. Okay.

Q. Does your doctor tell you about taking other pain medicines or about side effects of any pain medicines, or about other ways of dealing with your pain like hot baths or cool cloths?

A. No. I meditate a lot, but

Q. You meditate, alright good, if that makes you feel good. So they don't talk to you about any of that stuff.

A. No.

15. Is there anything about what the doctor or nurse tells you about treating your pain that is hard to understand?

A. No, because they haven't said anything to me about treating it yet.

Q. Okay.

16. What would make information about pain treatments easier to understand?

A. I guess what I can do to make it go away, I mean

Q. Okay.

A. Anything I can do to get some relief that would be nice.

Q. Get relief.

A. I used to could kind of ignore it a little bit but it's getting regular, it was you know, it's regular now.

Q. Now it's like chronic, it's always there. Okay.

A. Mm hmm.

17. If you didn't have an appointment for 2 weeks and had pain that really bothered you, what steps would you take?

A. I'd probably call here or come here.

Q. And go where?

A. Hmm?



- Q. Would you come to this clinic or go the emergency room?  
A. Well, I'd probably come see my doctor instead of going to the emergency room, because you know ain't no sense in trying to see when someone is treating you I think it's best to see the doctor that's treating you.  
Q. Okay good.

TREATMENT

---

Now I am going to ask you a couple of questions about the treatments you are receiving for your pain.

18. Has the doctor prescribed medicine for your cancer pain?  
A. Mm mm.  
Q. No. Um, so, the only thing you're taking is Tylenol. Nothing else, no Advil or anything like that?  
A. No.  
Q. And antibiotics  
A. Yeah the antibiotics, and I just got those because of the biopsy cause of the infection you know.  
Q. Right, but that happened a while ago.  
A. The drainage yes.  
Q. You got those antibiotics how long ago?  
A. I didn't get the prescription filled right away. I came to see him on the 30th, and I didn't get the prescription filled until, what's today? Oh, on the 4th.  
Q. Okay. Okay.

- 18b. Can you tell me how often you take the Tylenol and how much you take?  
A. Well, I try not take them because I've been looking forward to getting my chemo so I try not to take too much of medicine to overload my kidneys and liver and stuff you know. Because I know how the chemo and stuff you know that can make my kidneys shut down. So, you know I take....  
Q. Like how many Tylenol do you take a day?  
A. I if, you know if it's just usual if I'm having usual bad pain I would take maybe two but I've tried to cut them back because I've knowed that I'm going to be getting chemo so I would only take one and most of the time I try to suffer out with the pain because you know I don't want to overload my...

Q. Your body okay. So you take like one to two a day.

A. Mm hmm.

18c. What did you think the first time the doctor prescribed pain medicine for your cancer pain? Like when they told you to start taking Tylenol, what did you think?

A. I was already taking it. I didn't think anything.

Q. Okay, okay.

18d. Did anyone in your family or friends tell you what they thought about when you started taking the Tylenol for pain?

A. I haven't discussed it with anyone.

Q. Okay.

Sometimes people are bothered by some of the following thoughts. Can you tell me how much you wonder about any of these questions? What I'm going to do is read you a thought, these are thoughts. And then you tell me if you wonder about them not at all, a little, or a lot. Okay?

We'll start with the first one.

19. Can I become addicted to pain medicine?

Do you wonder about that        NOT AT ALL        A LITTLE        OR A LOT?

A. Well, I know you can if it's over strong.

Q. Okay um, so what would you say, not at all, a little, or a lot?

A. No, I don't wonder about it.

Q. You don't wonder about it.

20. Are my family members concerned about my using pain medicine?

Do you wonder about that        NOT AT ALL        A LITTLE        OR A LOT?

A. They're not concerned

Q. They're not concerned okay.

21. If I take strong pain medicines now, will they still work if my pain gets worse?

Do you ever wonder about that        NOT AT ALL        A LITTLE        OR A LOT?

A. Not at all. Because when I had my \* done you know like uh, my \* I lost all the bacteria out of my body and I had to bacteria pills and stuff like that I was in the hospital for a few days. And they had put me on a I forget this name of this medicine but it was pretty strong because they were trying to give it to me to knock me out and so I took a little more of it cause I was really in fevers and stuff like that

but then I told the nurse to when cut it out and just put me on regular Tylenol.

Q. When to cut it out. Okay.

22. If I talk about pain, will the doctor pay less attention to treating my cancer?

Do you wonder about that NOT AT ALL A LITTLE ...

A. No, because if I talk about pain they should pay more attention I think because evidently the cancer got to be the source of the pain.

Q. Okay. Good answer. Not at all.

23. Should I be strong and not lean on pain medicines?

Do you wonder about that NOT AT ALL A LITTLE OR A LOT?

A. I don't wonder at all about it. Not at all.

Q. Not at all. Okay.

24. Does taking strong pain medicine like morphine mean I am going to die soon?

Do you wonder about that NOT AT ALL A LITTLE OR A LOT?

A. Not at all because that's what I was on before when I was in the hospital, I was on morphine.

Q. Morphine. Okay.

25. Will my doctor or nurse think I am complaining if I keep telling them about pain that doesn't go away?

Do you ever wonder about that NOT AT ALL A LITTLE OR A LOT?

A. Well, it's kind of hard to answer that one because every time I come I'm seeing a different doctor now. I mean they converse with Dr. \* but you know.

Q. Right. Right.

A. I'm seeing different medical doctors well you know...

Q. But all in all they go to Dr. \*. Do you feel like that Dr. \* will think that you're complaining if you keep telling her about pain that doesn't go away do you ever think about that?

A. No. And I don't know about the gentleman doctor that I saw the other day, I don't know if he went to her or not but he just told me that he couldn't give me anything and I said well I was I told him all at home I was taking them because I was having a little bit more extra pain after he did the biopsy and he didn't give me a Tylenol or aspirin or nothing so I waited till I got home.

Q. Okay.

A. You know and so this is the first time this time I mentioned it to the doctor she I know she left the room immediately saying she was going to discuss it with Dr. \*. So.

26. Will the side effects from the pain medicine be worse than the pain?  
Do you ever wonder about that NOT AT ALL A LITTLE OR A LOT?
- A. Well, I guess it's something to wonder about. I never wondered about it because it could like I said damage my internal organs.
- Q. Right, so you do a little bit so you must say a little.
- A. Yes.

IF A LITTLE OR A LOT ASK : 26a. what side effects do you worry about the most? You just said damage your internal organs...

A. Kidney and liver liver failure while I'm on chemo. Kidney and liver.

Q. Okay.

27. Why doesn't my doctor know about my pain and take care of it?  
Do you wonder about that NOT AT ALL A LITTLE OR A LOT?
- A. Well I'm beginning to wonder! Yes I wonder now.
- Q. Okay, would you say a little or a lot?
- A. Well, I'm beginning to wonder a lot now because I've been mentioning it and now constantly and like I told that lady doctor it's getting worse and worse you know. Like it done ease up now but it was like a while ago you know seeing me grip \* my nails, \* and everything.
- Q. Yeah, I saw. yeah.

28. Will pain medicines work for me?  
Do you wonder about that NOT AT ALL A LITTLE OR A LOT?
- A. Well, I believe it will if they give me the right thing for the right pain.
- Q. Okay, good point. So not at all.
- A. No. Not at all.

29. What worries you the most about taking pain medicine?
- A. Well, like I said. Nothing if it works, but like what worries me if I get on chemo and then my organs begin to act up but that's my thought.
- Q. Okay, alright.

30. Sometimes people take pain medicine just as the doctor prescribes and sometimes times they take it some other way. Sometimes they take less than the doctor prescribes and sometimes they feel they may take more to get good enough relief.

How do you take your pain medicine? (READ FOLLOWING LIST)

- A. Well, I know you're supposed to take it like they say, but when I'm in pain I try to take it like they say but, you know, when I'm when it's easing up or whatever I tend to take less.
- Q. So you take less. Okay. so as the doctor prescribes it? less than the doctor prescribes it? or more than the doctor prescribes it?
- A. Well, regularly when I'm in pain but when the pain ease up I take less.
- Q. Less, okay.

IF LESS OR MORE:

30a. How do you decide when to take it and how much to take?

A. Well, I really got to be really hurting really bad you know. Really bad.

Q. Okay, alright.

A. Really bad.

Q. And when you're hurting really bad how many pills would you take?

A. Well, like I say, the Tylenol is extra strength so I've been taking one at a time.

Q. One at a time.

A. Yeah. One at a time.

Q. Alright. Yeah, okay.

31. Did you ever get a prescription for pain medicine and not have it filled?

A. Probably yes I did it's been so long.

Q. Recently. Like you know with this problem

A. No, uh uh. I haven't had anything for this. Nothing

Q. No. Okay.

32. Did you ever get a prescription for pain medicine filled, but not take the medicine?

A. I haven't did it for a long time back and antibiotics too. The doctor said that's why I have to come back so often

Q. Okay so pain pills and antibiotics

A. Yeah like \* supposed to take 'em all, I ain't took all these here see?

Q. Yeah.

(PATIENT KNOCKED SOMETHING OVER?)

A. Oh dear.

Q. That's okay, that's okay. So like a long time ago.

Q. That's why Dr. \* wants you to come back?

A. I don't know

Q. Okay.

IF YES: 32a. Why didn't you take the medicine when that happened?

A. Well, evidently I must have been feeling better.

Q. Okay.

IF IT SEEMS APPROPRIATE, ASK:

32b. If you did not take the medicine, what did you do about the pain?

A. It went away on it's own.

Q. It went away on it's own. Okay.

33. Does anyone ever take your medicine from you?

A. Ain't no one to take it from me.

Q. You're by yourself. Okay.

34. Has it been hard to get pain medicine?

A. I guess so, I'm not getting it! Not getting it.

Q. Right, right I was waiting for that answer! Okay. I was expecting that kind of answer

IF YES: 34a. What's been hard about getting pain medicine?

A. Well I guess they figure, I was having you know cause when sometimes I guess the tumor grow it itches and I scratch and it's horrible and I'm sore. So I guess they figured it was just the extension of my skin being stretched from the growth of the tumor. But like I said it's gone beyond that now. It's into a fiery, burning, hurting, constant thing. It's beyond growth.

Q. Um, okay. So that's because I could say:

- Too much money?

- Hard to get to the pharmacy or store?

- Someone told you not to get the medicine?

- Fear

A. No,

Q. No, you told what you told me and that's it okay. Um, any other problems trying to get pain medicine besides that or...

A. Well, lessen I don't have the money and...

Q. Okay.

35. Have you had any problems with your pain medicine although you're not really

taking but like when you take the Tylenol does it ever make you feel sick to your stomach or groggy or constipated or anything?

A. No, but I want, I makes myself, I will myself to sleep anyway. Cause when I take it I just want to go to sleep and wake up and let the pain be gone.

Q. Okay. Um, lets go on, we're almost done.

A. Alright \* ... papers

Q. Oh I know, a lot.. but these are good questions, they're good.

A. Yeah, they are.

36. A lot of people use other ways of dealing with their pain besides what they were told to do in the hospital or clinic.

For example, people use

Q. prayer

A. Yes.

Q. special teas

A. Well, I don't do the special teas but I love all kinds of teas, I take ginseng, I love herbal teas too.

Q. Okay, massage, special foods

A. I don't get massages.

Q. Any special foods?

A. Oh I love vegetables. I think vegetables is a healing thing.

Q. Okay, vitamins?

A. Yes.

Q. Okay, alcohol?

A. Mm, I drink beer and a little liquor, but not for the pain, for the pleasure!

Q. For the pleasure, relaxation?

A. Yes, it's meditation.

Q. Meditation. Any non-prescription drugs?

A. Nothing but Tylenol.

Q. Okay.

Q. What other ways do you use to help you cope with your pain?

A. Just mainly sleep and Tylenol.

Q. Okay. Anything else?

A. No.

IF PT. IDENTIFIES A WAY OF COPING ASK: 36a. How well does this work for you?

A. Pretty good, you know,

sometimes it's a struggle  
like I say like last night was  
a bad night

Q. Okay.

A. This morning and...

37. When you have pain and it is being treated, what do you expect to happen? Do you expect:
- The pain to disappear completely
  - The pain to become bearable
  - To be able to work?
  - Or Something else?
- A. I expect it to go away.
- Q. Okay.
- A. If you're being treated for pain, I expect it to go away.
- Q. Any, anything else, no. You just expect it to go away.
38. Do you ever think that other patients get better treatment for their pain than you do?
- A. No I haven't given it a lot of thought.
- Q. Okay.
39. I'm going to show you what we call a pain scale, this is what we used earlier, the scale of the, you know, one through ten here.
- A. Mm mm. We done filled one out already.
- Q. I know, but just, there's another question with this.
- Q. Does your doctor or nurse ever use this or something like this to ask about your pain?
- A. No. Just only to describe where the tumors were.
- Q. But they never used a scale to describe.
- A. No, not a scale or anything.
40. Using that scale- How bad is your pain right now, zero to ten?
- A. It done ease up now easy, well what is that like a one?
- Q. Well,
- A. You can tell when it gets worse, it's easing up some it was burning really bad..
- Q. So, like right now what would you describe your pain?
- A. Right now, about a one
- Q. A one.
- A. It's a little straggly.
- Q. Okay.



41. How bad would the pain have to be (like what number) before you'd make a special call to the doctor or the nurse or the clinic?
- A. A ten.
- Q. Ten.
- A. And it's been that way but I haven't I been trying to wait till I come back you know come over here for my appointment.
42. What number on this scale is your pain when you feel that your pain medicine is working for you? Like when you take the Tylenol, what number would you rate your pain when it's working?
- A. Well, it be a ten when I take it so
- Q. And then after you take it and it starts to have effect
- A. I'd say within 30 minutes I would rate it about a 5 or so because I put myself into a the state, I been putting my mind into a meditative state so I can go to sleep it relaxes myself.
- Q. That's good you have such power with your mind
- A. Yup.
43. Um, okay. Are there things that somebody could do to make your pain better?
- A. No nothing but get rid of this cancer.
- Q. Alright
- A. The cancer got to go before the pain get better.
- Q. Is there anything you wish people would do for you to help you with your pain?
- A. No more than the doctor prescribe something and really check me and take me seriously cause the reason I figure the pain is beginning so regular the cancer is getting worse it's gotta be because I'm burning my breast like I said like a liquid fire, like fire inside of me burning.
- Q. Fire inside you okay.

*IF IT SEEMS APPROPRIATE, ASK:*

- (43a) 1. Is there anyone who would be willing to help you? Do you feel?
- A. What, if I get sick?
- Q. Yeah, like with the pain?
- A. I don't know anyone I guess unless it's a doctor you know.
- (43a) 2. Who would you most LIKE to help you?
- A. I guess my doctor, I mean you know.
- Q. Okay.

44. Do you have any worries about the pain medicine that we haven't talked about?  
A. No, not yet.  
Q. Okay.
45. Do you think your family or friends or anybody close to you would have any worries about pain medicine that we haven't talked about?  
Q. No.
46. What do you see as the benefits to you in taking your pain medicine?  
•is it easier to do chores?  
•is it easier to do things with friends or family?  
•do you feel better?  
•are you in a better mood?  
A. I feel better, I'm easily cope with myself because I tell you the way this fire hit me I just want to I could just come out of my body you know.  
Q. Really. That sounds pretty bad.

### MEANING OF PAIN

---

Now I'm going to ask you some questions about what pain means to you.

47. Pain means different things to people depending on their past experiences, beliefs, and thoughts. How would you finish this sentence? To me, pain means \_\_\_\_\_.  
A. Oh God. Pain means, uh, a lack of concentration, a lack of motor skills, a lack of a lack of you know, just,  
Q. Okay, and like the pain you feel in your breast,  
A. Yes.  
Q. What does it mean to you? Through your beliefs and your thoughts.  
A. It means that I can't correspond right, I mean, you know, all I want all I want to do is sit down and try to quench that that fire that's burning inside of me. I can't function properly, you know.  
Q. Okay.  
A. But if I had to I guess I could, like if I was driving or something I was in pain I'd have to have a strong mind to function, but when I'm at home if I'm in pain or something I don't think about going out doing anything all I want to do is ease the pain.  
Q. Right.
48. Many people, when they learn they have cancer ask "why me?" and wonder if there's some reason they got cancer. Do you ever have thoughts about why you

have cancer or cancer pain?

- A. Well, no because when I first got cancer I thought alright, I was afraid, I cried for two minutes and that was it, two seconds and never cried again, that 's why I think I'm so strong now. But I figure it's probably because of the sun, and when I was little, you know we lived on farmland and it could have something to do with the chemicals and like the DDT, and the chemicals I thought about that and the climate. But, like I know so many people getting tumors and stuff and some of them are lucky, they are not denying, you know, and so I figure it's probably the climate, and the chemicals in the food. Over processed food, you know because it's young children, older people, there's a lot of people getting tumors and having cancer.
- Q. Right, right.

49. How does your pain change your life?

A. It makes me cranky,

Q. Yeah,

A. And it, it well, it takes, if it's regular it takes my activity away you know. It slows me down.

Q. Slows you down.

Q. Are there people in your home who depend on you or who need you to do things for them that you can no longer do because of pain?

A. No.

Q. No.

IF YES: 49a. Have you told the doctor about these changes in your life?

A. Hmm.

Q. That it makes you cranky, and makes you slow down.

A. No. Like I say, you know, I brought it up two or three times and you know, the strongest response I got was you know she said she'd have to talk to the doctor again about Dr \*, so you know....

Q. Okay.

☆50. We're trying to design a program to provide information for patients who have cancer pain. What information do you think should we include?

A. About cancer pain?

Q. Yeah.

A. I think when a person say if they say they are in pain I think the doctor should listen to them more carefully and ask them about their pain and try to understand about it.

Q. Okay.

- Q. What could we tell patients who start to have pain like in this clinic that would make their pain better?
- A. To try to have a strong mind, and talk to their doctor about it because I guess you know if the pain isn't so bearable that over the counter drugs can't help they have to you know turn to their doctor and you know.
- Q. Okay.
- Q. These last few questions I have are for background purposes. Let me know if you do not want to answer a question. Okay?

#### DEMOGRAPHIC QUESTIONS

---

51. Are you currently:  
Single Married Widowed Separated or Divorced?
- A. Um, I was separated, but I am married. And that's why I said I'm seeing a counsel. My husband had left me and then he found out that you know about the cancer and stuff so he came back here got me a apartment and so he's back living with me and he's the one brings me back and forth when he can you know take it off from his job.
- Q. Is he here today?
- A. Yeah he brought me today and
- Q. That's good
- A. The marriage life having to \* 22 years, but you know, but I'm going to tell you, if I didn't need him for transportational purpose I would still let him go. Oh, they ain't going to hear that are they, you're going to take that off?
- Q. We'll ignore that. Okay.
52. Which of the following best describes your current job status?  
Employed, full-time  
Employed, part-time  
A Homemaker  
Retired  
Unemployed  
A Student  
or something else?
- A. Unemployed.
- Q. Unemployed

IF UNEMPLOYED OR RETIRED:

52c. Um, what was your previous job?

- A. Um, maid work or dietetic cook.  
Q. Now you're a Keys person.  
A. Well, I, was a dietetic person, well Keys dietetic cook.  
Q. Yes. Cool.

- IF MARRIED: 52d. What is your spouse's job?  
A. Well, he works on a for the sanitation department.  
Q. Okay.

53. What was your highest grade you finished in school?  
A. Uh, fifth.

54. Do you have any children?  
A. Yes, a son. 30 years old.  
Q. 30 years old.

- IF YES: 54a. And is he living with you?  
A. No he's not. He's in Arkansas.

- ☆55. I'm going to read a list of people, when I'm finished could you please tell me all the people from the list who you live with?

Do you live with: your husband...

- A. Yes.  
Q. your boyfriend, your children, your parent(s) or parent(s)-in-law, do you live alone, or with other people not on this list?  
A. With my husband, he moved back in with me.  
Q. Alright, so it's your husband.

56. What is the total number of people who live with you in your household, including yourself?

- A. Just us two. Just my husband and I.  
Q. Okay, it's the last page.

57. From the following list, can you tell me your race or ethnicity?  
White, not Hispanic  
African American or Black, not Hispanic  
Asian or Pacific Islander

Native American  
Hispanic regardless of race

A. Well, I'm black, but I can't, cause if I tell you my ethnic background I would be Afro-- How would I put that Afro-

Q. Native

A. Native, and

Q. American

A. Yeah, Caucasian or whatever

Q. Yeah, okay.

IF HISPANIC: 56a. Can you tell me what country or countries your family originally came from?

A. Well, all I know is my grandmother, she told me you know they was from Oklahoma here in the states you know. She didn't talk about you know, I never know about my grandfather never talked about African you know the other countries that we was from.

☆58. What is your family income? How much you and your husband makes. Is it...

A. Well, I was trying to get food stamps and I gave him a paper that asked him about his income he refused to give that to me so I went back to apply for food stamps, but he's private about his life at this point.

Q. Alright, so he's private, so private.

A. Yes that's why I say you know...

Q. You're applying though for subsidies

A. Yes, I'm going through changes, you know, some changes that's why I say I wouldn't be living with him if I could do better.

Q. So you're right now you're applying for social security

A. Yes.

Q. Social security. Okay. Thank you very much for your help. You're you're a nice...

## ENTREVISTA ESTRUCTURADA

Pt. no. 004

**AL PACIENTE:** Yo trabajo con su médico y con el Grupo de Investigación del Dolor de la Universidad de Wisconsin. Estamos desarrollando materiales para ayudar a los pacientes de cáncer y a sus familias a entender y manejar el dolor de cáncer. Estamos hablando con varios pacientes de cáncer, pidiéndoles su ayuda con los materiales, para así garantizar que la información es completa y fácil de entender. Me gustaría hablar con usted sobre su experiencia con el cáncer y el dolor de cáncer. Sus ideas serán muy valiosas para nosotros. Estas preguntas no son ningún tipo de examen, no hay respuestas correctas o equivocadas. Sus opiniones y sugerencias son muy importantes para nosotros. Por favor, dígame si no desea responder alguna de las preguntas. Todas sus respuestas son confidenciales. Su médico no escuchará ninguna de sus respuestas. Sus respuestas no afectarán en absoluto su tratamiento médico.

INFORMACION / COMUNICACION

1. Probablemente, usted habrá recibido diferentes tipos de información sobre el cáncer y el dolor de cáncer. A continuación voy a leerle una lista de las formas en que las personas reciben información sobre el cáncer.

De esta lista, ¿podría decirme dónde obtuvo la mayoría de la información sobre el cáncer y el dolor de cáncer?

¿Fue...

hablando con el médico o la enfermera? *Hablando con el médico.*

hablando con sus familiares? *A, bueno, Yo hable poco con mis familiares, porque tengo poca familia.*

hablando con sus amigos? *No*

hablando con su sacerdote, pastor, o miembros de su iglesia? *No, No*

hablando con miembros de la comunidad? *No, Yo no le comente a nadie de eso, yo estaba aquí en el hospital, ya yo me movi y he seguido mi tratamiento algunas personas si qué dijeron qué yo tenia el cancer, y yo actuo como si no tuviera nada.*

hablando con personas que tienen o han tenido cáncer? *He hablado con otras personas qué tienen cancer. Y hemos recibido alivio, alivio.*

leyendo folletos informativos? *Bueno, he leído, pero muy poco, porque total ya una vez que tú éstas enfermo ya no tiene.*

viendo videos? *No, no he visto videos.*

viendo programas de televisión? *Viendo programs de televisión y entreteniendome, jugando domino, jugando domino.*

viendo anuncios? *Viendo los anuncios y eso, sí.*

escuchando programas de radio? *De radio, pero no de cancer, sino programas de radio, de televisión pero no de cancer.*

a través de alguna otra fuente? *No, no entiendo eso. Otra vez? De otra fuente, no.*

**Si responde "Otra fuente":**

- 1a. **¿Podría decirme algo más sobre esa fuente de información?** *Del hospital, ya hecho memoria y ya hancido reunidos aquí varios doctores y se reunieron varias veces.*

2. **¿Fue útil esta información? . Si, bueno, sobre la enfermeda si.**

- Si responde SÍ:** 2a. **¿Podría decirme qué tipo de información fue más útil y por qué?** *Bueno, qué cuando yo me vinieron los anáisis y la placa me dijeron qué tenia cancer, cancer en el pulmon y qué habia qué injectarme terapia, chemoterapia, y bueno eso es otra cosa. No.*

- Si responde NO:** 2b. **¿Porqué la información no le fue útil?**

3. **¿Ha hablado sobre su cáncer con miembros de su familia, de su iglesia, comunidad, o sus amigos?** *Si, He hablado con todo el mundo.*

- Si responde SÍ:** 3a. **¿Específicamente, con quién/quienes habló?** *Con mi hijo, con la qué era la ex-esposa mia, y con varios amigos, y con el pastor, no es pastor, con el sacerdote. Sí.*

- 3b. **¿Qué le dijo/dijeron a usted sobre su dolor?** *Bueno, ellos no me pueden decir nada de mi dolor, por qué el dolor lo tengo yo, ni nada ellos no me pueden decir nada, el dolor esta ahí, no me pueden decir nada.*

- 3c. **¿Le han hecho sugerencias de como debe de enfrentarse a su dolor?** *No, qué yo no le doy importancia. Si te pones a darle importancia te pones loco.*



**Si responde Sí: (3c)1. ¿Cuáles fueron algunas de las sugerencias?**

**(3c)2. ¿Siguió sus sugerencias?**

4. **¿Cuál sería la mejor manera, o maneras, para usted de obtener información sobre el dolor de cáncer?** *Bueno, la mejor manera, es con la que estoy usando, viniendo el médico puntualmente a todos los appointments que me han dado, me han dado.*
5. **¿Cuál sería la mejor manera, o maneras, para su familia y los que le cuidan de obtener información sobre el dolor de cáncer?** *De hecho no darle importancia, lo mejor.*
6. **¿En quién confía más a la hora de recibir información correcta sobre el dolor de cáncer?** *Bueno, la doctora que me atiende, es la que yo recibo mejor información.*  
**[SI ES NECESARIO, SUGIERA: Por ejemplo, ¿su enfermera, médico, familia, o un amigo? La doctora, la doctora.**
7. **¿Quién es la primera persona con quien habló sobre un problema físico?** *Bueno, con amistades, como que vivo solo, pues hable con amigos.*  
**[SI NECESITA EXPLICACION: ¿problemas con su cuerpo?]**
8. **¿Podría decirme por qué habló con esa persona primero?** *Porque como vine con amigos aquí se enteraron, por qué vine con un amigo aquí, vine al hospital con un amigo. Hablé.*



9. ¿Es difícil para usted hablar de sus problemas físicos?

*No, no eso no tiene importancia para mí.*

[SI NECESITA EXPLICACION: ¿problemas con su cuerpo?] *No, no tiene ni problemas.*

**Si responde Sí:** 9a. ¿Porqué le es difícil hablar de sus problemas físicos?

10. ¿Es difícil para usted hablar sobre el cáncer que usted tiene?

*No, no es difícil.*

**Si responde Sí:** 10a. ¿Qué es lo que se le hace difícil al hablar sobre el cáncer que usted tiene?

11. ¿Es difícil para usted hablar sobre el dolor de cáncer que usted tiene?

*No es difícil, quiere decir no tenga, no tiene pena, que pena voy a tener si de todas maneras esta muerto.*

**Si responde Sí:** 11a. ¿Qué es lo que se le hace difícil al hablar sobre el dolor de cáncer?

11b. ¿Qué cosa le haría más fácil el hablar del dolor de cáncer?

12. ¿Habla con su médico o enfermera sobre su dolor de cáncer?

*Ah, sí, con la doctora sí hablo, con la del médico, con la doctora.*

**Si responde Sí:** 12a. ¿Con quién? ¿Con los dos? *No, yo no tengo, bueno, con la enfermera por que es la que pone la chemoterapia.*

12b. ¿Le preguntan su médico o enfermera sobre el dolor, o en general es usted el que lo menciona primero? *Bueno, en general cairia bueno el qué lo menciona primero soy yo.*

**[SI ES NECESARIO, PREGUNTE:**

**Cuando habla con su médico o su enfermera sobre el dolor, ¿le preguntan a usted sobre su dolor, o es usted quien primero menciona el tema del dolor?]**

- 12c. ¿Qué pasó la última vez que usted habló con el médico o enfermera sobre el dolor de cáncer? ¿Entendieron en qué consistía su dolor?** *Entendio, y me mando una pastilla para calmar el dolor.*

**Si responde SÍ: (12c)1.**

**¿Qué le hace pensar que él o ella entendió en qué consistía su dolor?** *Ah, en qué, en qué, vuelva again? Bueno, consistia en ella, ya sabe, ella debe saber que el cancer da dolor, bueno viendola fisicamente qué le da como una vena vaya, algo que quiere tratar de resolver.*

**Si responde NO: (12c)2.**

**¿Qué le hace pensar que él o ella no entendió qué consistía su dolor?**

- 13. ¿Hay alguna otra persona con la que usted hable sobre su dolor?**  
*Sí, amistades, amigos y, y el hijo mio.*

14. ¿Qué le dicen su médico o enfermera sobre el tratamiento de su dolor?

*Qué van bien, qué voy bien.*

[SI ES NECESARIO, EXPLIQUE:

Por ejemplo, ¿le comenta su médico o enfermera sobre la posibilidad de tomar medicinas para el dolor? ¿Sobre sus efectos secundarios? ¿O sobre otras formas de combatir el dolor, tales como baños calientes o compresas frías?]

*Sí, me manda medicamento sí, bueno no en eso no. No están muy bien ellos, no ahí hay un problema eso es verdad de qué no hay sugerencia, debe de haber mas sugerencia.*

15. De las cosas que le dicen su médico o enfermera sobre el tratamiento de su dolor, ¿hay alguna difícil de entender?

*Como dice? Bueno, ha habido tan poca cosa, ha habido tan poca comunicación, que no que todo lo he entendido.*

16. ¿Qué se podría hacer para que la información sobre los tratamientos fuera más fácil de entender?

*Ahí sí, yo no se cual sería la información, de que más fácil para entender, ahí si yo no, es que no ahí si no poco.*

17. Suponga que tiene dolor intenso, y que no tiene planeado ver a su médico durante las próximas 2 semanas. ¿Qué haría usted?

*Eso es otra cosa, que no se que haría, que no se que haría si tuviera un dolor intenso claro, ella aquí la doctora me ha dicho que me daba el teléfono para que llame a la clínica, y entonces venir aquí al hospital. A hacer, al hospital a coger el como es que se dice, a coger por, por emergencia. Ni modo de irme a otro médico particular, a empezar de nuevo, porque había que empezar de nuevo, hacer todos los papeles eso es otro problema.*

[SI ES NECESARIO, PREGUNTE:

¿Qué pasos seguiría?

## TRATAMIENTO

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Ahora voy a hacerle una serie de preguntas sobre los tratamientos que usted recibe para combatir su dolor.18. ¿Le ha recetado su médico alguna medicina contra el dolor de cáncer?

*No, no, bueno la qué me recomendo fue la terapia. Esa es medicina o qué?*

*Contra el dolor del cancer esta es qué, pedí ahora la pastillita esa y otra qué y el tylenol y ya van varias como se llama el tylenol ese otro tylenol qué hay qué tiene el codein. Ese otro. Sí, esa es la verdad.*

*Si responde Sí:* 18a. ¿Puede decirme qué le recetó? .

SI ES NECESARIO, PREGUNTE: ¿Recuerda el nombre de la medicina?

18b. ¿Puede decirme cada cuando la toma, y cuanta medicina toma?

*Bueno, la codein no la tomo, porque me duermo mucho. Entonces lo qué tomo es el tylenol.*

18c. ¿Qué pensó la primera vez que el médico le recetó medicina para su dolor de cáncer?

*No, si no me mandaron medicina para el can, para el dolor, fue fue qué me mandaron ese y bueno, y aver si me hacienta y bueno, qué me dormia mucho y entonces lo deje de tomar y entonces le pedi qué me mandara tylenol.*

18d. ¿Le dijo alguien de su familia lo que pensaba?

*No, no porque nunca he tenido medicina. Esta enfermera nunca tiene medicina.*

En ocasiones las personas se sienten molestas con algunas de las siguientes ideas. ¿Puede decirme que tan seguido piensa en las siguientes preguntas?

19. **¿Puedo convertirme en un adicto a las medicinas para el dolor?**

**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Bueno ya, yo no he pensado "naa" cuando veo qué una cosa me esta cayendo "mal", no la tomo "mai" y prefiero aguantarme cualquier dolor como lo hice con la ine que me dormí, no la tome más. Algunas veces.*

20. **¿Está mi familia preocupada porque utilizo una medicina contra el dolor?**

**¿Se pregunta usted sobre esto: NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Algunas Veces.*

21. **Si tomo medicina fuerte para el dolor ahora, ¿va a servir aún la medicina cuando mi dolor empeore?**

*Vuelvele, vuelvele?*

**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Algunas veces.*

22. **Si hablo del dolor con mi médico, ¿prestará menos atención al tratamiento de mi cáncer?**

*Vuelvele, vuelvele?*

**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Bueno, algunas veces también, el siempre esta preocupado.*

23. **¿Debo ser fuerte y no depender de las medicinas para el dolor?**

**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Algunas veces. También.*

24. **¿El tomar una medicina fuerte para el dolor como la morfina significa que me voy a morir pronto?**

**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Algunas veces si. Pero yo no tomo morfina.*

25. **Si les digo a mi médico o enfermera que mi dolor no desaparece, ¿pensarán que me estoy quejando innecesariamente?**

**¿Se**

**pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**

*Bueno, algunas veces, pero si piensa una de qué se esta uno quejando, si ya es mentira.*

26. **¿Son los efectos secundarios de las medicinas para el dolor peores que el dolor?**  
**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**  
*Cómo, cómo es qué dice? Algunas veces.*
- Si responde ALGUNAS VECES o FRECUENTEMENTE, pregunte:*
- 26a. **¿Cuáles son los efectos secundarios que más le preocupan? Cuales son los efectos secundario?**  
*Bueno no ami lo qué me preocupa, los secundarios son el problema, la soledad, la soledad o ir por un ojo o tener el dolor penentemente.*
27. **¿Por qué mi médico no se da cuenta que tengo dolor y por qué no lo trata?**  
**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**  
*Ese es el sacrificio, porque es qué el lio de él, él problema del médico no es tan fácil de qué se preocupe, porque es qué no puede tanpoco hacer tanta fuerza y esta cosa. Algunas veces.*
28. **¿Servirán las medicinas para el dolor en mi caso?**  
**¿Se pregunta usted sobre esto NUNCA ALGUNAS VECES o FRECUENTEMENTE?**  
*Ya, algunas veces también porque siempre, ésta es un enfermedad yo qué ni se una enfermedad, que nise no, no suena bién.*
29. **¿Qué es lo que más le preocupa sobre las medicinas para el dolor?**  
*El vicio, el vicio y qué no sirvan ya después, y vaya, como un avito .Y ya después no sirvan, después no te quitan el dolor.*
30. **En ocasiones la gente toma medicinas para el dolor siguiendo la receta del médico, y en ocasiones las toma de otra manera. Algunas veces toma menos medicinas para el dolor de las recetadas por el médico, y otras veces cree que es necesario tomar más para sentirse aliviada.**  
*Bueno regular, como la receto el médico o meno, lo que hay semanas que tú tiene, me aviento un tylenol, hay veces qué tomo ma y hay veces qué tomo meno, hay veces qué meno. No, no nunca más.*
- ¿Cómo toma usted la medicina para el dolor? (LEA LA SIGUIENTE LISTA)**  
**-¿Como la recetó el médico?**  
**-¿Menos de la que recetó el médico?**  
**-¿Más de la que recetó el médico?**



Si responde MENOS o MAS: 30a. ¿Cómo decide qué cantidad de medicina tiene que tomar y cuándo tiene que hacerlo? Cuando que como dice? Eso yo no lo entiendo. Una do pastilas aveces una o dos pastillas, poquito más.

SI ES NECESARIO, EXPLIQUE:  
¿Cuántas pastillas o cuánto líquido?

31. **¿Le recetaron alguna vez una medicina para el dolor que no fue a recoger ?**

*No, siempre recoge, siempre la he recogido.*

Si responde Sí: 31a. Por favor, dígame porqué no la fue a recoger.

32. **¿Alguna vez fue a recoger alguna medicina para el dolor que le recetaron pero no la tomó?**

*No, no siempre la tome. No, siempre la tome siempre la he tomado bueno, no se por ahí la codina la deja de tomar, hacies qué hay un viaje por ahí qué deje de tomar . Codina, codina.*

Si responde Sí: 32a. Por favor, dígame porqué no la tomó. Me dormia, me daba mucho down.

SI LE PARECE ADECUADO, PREGUNTE:

32b. Si usted no tomó la medicina, que hizo usted con su dolor?  
*Cambie también de pastillas, tome tylenol pero tylenol sin codeina. Bueno, tú la pones.*

33. **¿Alguien le ha quitado alguna vez sus medicinas? No.**

Si responde Sí: 33a. ¿Cuál es la razón o las razones por las que le han quitado las medicinas? (LEA LA SIGUIENTE LISTA)  
-no hay ninguna razón.  
-para impedir que tome demasiada medicina.  
-para impedir que tome ese tipo de medicina para el dolor.  
-por que la persona que me las quita tiene un problema de adicción.

34. **¿Le ha sido difícil conseguir medicinas para el dolor? No.**

*Si responde Sí:* 34a. **¿Qué dificultades ha tenido en conseguir medicinas para el dolor?**

SI ES NECESARIO, SUGIERA:

¿Demasiado caras?

¿Es difícil para mí el ir a la farmacia o tienda?

¿Alguien le dijo que no comprara la medicina?

¿Miedo?

CUANDO EL PACIENTE IDENTIFIQUE UNA DIFICULTAD, DOCUMENTELA Y PREGUNTE:

**¿Tuvo algún otro problema a la hora de conseguir las medicinas para el dolor?**

HASTA QUE EL PACIENTE NO TENGA NADA MÁS QUE DECIR.

35. **¿Ha tenido algún problema con las medicinas para el dolor (tal como estreñimiento, náuseas, mareos)?** He tenido estreñimiento, y he tenido mareo.

*Si responde Sí:* 35a. **¿Qué ocurrió? Estreñimiento. Y mareo sí.**

35b. **¿Qué hizo usted? Tomar otra medicina para poder corregir, y otra medicina para el asunto del mareo.**

35c. **¿Alguien le dijo que usted podía tener estos problemas?**

*Sí, la doctora, la enfermera. La enfermera y la doctora porque ni de la farmacia dijo nada.*

*Si responde Sí:* (35c)1. **¿Quién?**

SI ES NECESARIO, SUGIERA:

¿Su médico?

¿Su enfermera?

¿Su farmacéutico?

¿Otra persona?

SI EL PACIENTE IDENTIFICA UNA FUENTE DE INFORMACION, DOCUMENTELA Y PREGUNTE:

**¿Alguien más?**

HASTA QUE EL PACIENTE NO TENGA NADA MÁS QUE DECIR.

36. Muchas personas usan otros métodos para combatir o enfrentar el dolor además de los ofrecidos en el hospital o clínica.

Por ejemplo, muchas personas usan

- oraciones
- tés especiales
- masajes
- comidas especiales
- vitaminas
- alcohol
- relajación, o
- medicamentos que no necesitan receta

*Bueno, no ahí yo "na" "ma" qué vitamina qué esto tomando, vitaminas y comida, bueno especiales ninguna, no hay comida no hay repollo, birotos. No.*

¿Qué otros medios utiliza usted para combatir o enfrentar el dolor?

*Bueno, no tranquilidad. Nama no hay otra cosa.*

**SI EL PACIENTE IDENTIFICA ALGUN MEDIO, DOCUMENTELO Y PREGUNTE:**

¿Alguno más?

**HASTA QUE EL PACIENTE NO TENGA NADA MAS QUE DECIR.**

**SI EL PACIENTE IDENTIFICA ALGUN MEDIO, PREGUNTE**

36a. ¿Que tan buenos son los resultados que ha obtenido?

37. Cuándo usted tiene dolor y éste es tratado, ¿qué espera usted?

- Que el dolor desaparezca por completo
- Que el dolor sea más tolerable
- Poder volver a trabajar
- Alguna otra cosa

*Bueno, alguna otra cosa y volver a trabajar, vaya qué espero yo qué se me quite, qué se me quite y ya desaparezca por completo "na", "na" mas tolerable qué el dolor seha mas tolerable. Sí. Sí, esto también.*

**Si responde "ALGUNA OTRA COSA": 37a. ¿Podría decirme algo más de lo que espera?**

**Bueno, estar mas contento y estar más feliz.**

38. ¿Cree que otros pacientes reciben mejor tratamiento para el dolor que el que recibe usted? No.

**Si responde Sí:** 38a. ¿Por qué cree que otros pacientes reciben mejor tratamiento?

39. Ahora le voy a mostrar una escala de dolor, [muestre el impreso BPI]. ¿Utilizan su médico o enfermera esto o algo parecido para preguntarle sobre su dolor? Sí.

**Si responde Sí:** 39a. ¿Le ayuda esto a hablar de su dolor? Sí.

40. Según esta escala, ¿qué tan fuerte es su dolor en este momento? *En el cinco.*

41. ¿A qué punto (a qué número) tiene que llegar el dolor para que usted llame al médico, la enfermera o la clínica? *Al diez, al ocho, al die.*

42. ¿A qué punto (a qué número en la escala) llega su dolor cuando piensa que la medicina para el dolor está funcionando? *Cómo dice?*

**SI ES NECESARIO, EXPLIQUE:** Si recibe tratamiento contra el dolor, ¿a qué punto debería llegar su dolor si el tratamiento tuviera éxito? *Al tres.*

43. ¿Qué podrían hacer otras personas para aliviar su dolor? *Nada.*

**SI ES NECESARIO, EXPLIQUE:** ¿Hay algo que le gustaría que alguien hiciera para aliviar su dolor? *No, creo que nada.*

**Si responde Sí:** 43a. ¿Qué cosas?

**SI LE PARECE OPORTUNO, PREGUNTE:**

(43a)1. ¿Hay alguien dispuesto a ayudarle? *Nada. Bueno, eso no creo yo a meno que no sea la doctora.*

(43a)2.       ¿Quién es la persona que MAS LE GUSTARÍA que le ayudase? *Bueno un familiar mío, pero no lo tengo.*

44.    ¿Tiene usted algunas preocupaciones sobre las medicinas para el dolor de las que no hayamos hablado todavía?

*Bueno, si hay preocupación, de la preocupación es la que no hemos hablado todavía. Haber si viene una mas mejor no, una mejor.*

45.    ¿Tiene su familia algunas preocupaciones sobre las medicinas para el dolor de las que no hayamos hablado todavía? *No, no, ellos no tienen preocupación.*

46.    ¿Para usted, cuáles son los beneficios de tomar medicinas para el dolor?  
POR EJEMPLO:

- es más fácil hacer las tareas.
- es más fácil hacer cosas con la familia.
- sentirse mejor.
- estar de mejor humor.

*No, yo no hago tareas , yo lo qué hago es tomo una pastilla este calmante. Si ésta tiene un problema de la este, ésta ésta hablando con una persona qué vive solo, y eso es el problema qué es diferente a lo qué tiene mujer, hijo, al qué vive solo. Sentirse mejor es lo bonito, éstar de mejor humor, digo que hay cosas qué le bienen bien, quiere decir qué a mi me viene bien, porque pa mi solo. Pero cuando tú tienes la enfermedad y tienes familia, y tienes esto y tienes distinto carácter, y tienes amor pa la vida ,y tienes distintas edades. Y eso radica todo en las edades y en todo qué tú tenga y él otro qué va a perder la fortuna, y él otro qué va a vivir solo. Tú lo pangas ahí.*

## SIGNIFICADO DEL DOLOR

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Ahora voy a hacerle unas preguntas sobre lo que el dolor significa para usted.

47. El dolor tiene significados diferentes para cada persona según sus experiencias y creencias. ¿Cómo terminaría usted esta frase? Para mí, el dolor significa \_\_\_\_\_  
*Nada, nada. Nada aguanta el dolor nada.*

48. Muchas personas, cuando descubren que tienen cáncer, se preguntan ¿por qué yo? y piensan si existe alguna razón por la que ellos tienen cáncer. ¿Piensa usted alguna vez por qué tiene cáncer o dolor de cáncer? *Bueno, porque esa es la enfermedad que esta y que le cae a cualquiera como al que le cae la lotería.*

*Si responde Sí:* 48a. ¿Puede decirme algo sobre sus pensamientos? *Sí, que no, no yo que no no que trato de que no tenga ningun pensamiento por eso a cualquiera le cae cancer. Qué hay miles y mile millones con cancer que esto es una cosa pues, si no figurete no cupieramos en la tierra.*

49. ¿Cómo ha cambiando su vida a causa del dolor? *Bueno, esa sí esa ha cambiado mucho, porque debido que tiene dolor usted tiene un malestar que no puede reir ,y no puede bailar y no puede hacer veinte cosa.*

*SI ES NECESARIO, EXPLIQUE:* Por ejemplo, ¿hay personas en su casa que dependan de usted, o qué necesiten que usted haga cosas que ya no puede hacer debido al dolor? *Ya tu veiz yo no, no si ha cosa que no puedo hacer debido al dolor la afecta. cocinar.*

*Si responde Sí:* 49a. ¿Ha hablado con su médico sobre estos cambios en su vida? *No, no.*

50. Queremos diseñar un programa para ofrecer información a los pacientes con dolor de cáncer. ¿Qué información deberíamos incluir?

*Para el dolor de cancer? Conformidad, eso conformidad. Bueno porque de la otra forma se vuelve loco. Conformidad, quiere decir que estas conforme con el dolor, porque no te lo puedes quitar. Ni nadie puede decir porque esta ahí, ni vamos aplicarle este aparato tiene que tener conformidad, sino te vuelve loco. Conformidad, tranquilidad, todo el tiempo.*

**SI ES NECESARIO, EXPLIQUE:**

**¿Qué podemos decir a los pacientes que empiezan a tener dolor para que se sientan mejor?**

**TENGO ALGUNAS PREGUNTAS DE INFORMACION GENERAL. POR FAVOR, DIGAME SI NO DESEA CONTESTAR ALGUNA DE LAS PREGUNTAS.**

**(LEA TODAS LAS PREGUNTAS DE INFORMACION DEMOGRAFICA.)**

**PREGUNTAS DEMOGRAFICAS**

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**51. ¿Es usted:**

**soltero/a    casado/a    viudo/a    separado/a    divorciado/a?**  
**Soltero.**

**52. ¿Cuál de las siguientes afirmaciones describe mejor su situación laboral?**

**Trabajador de tiempo completo**  
**Trabajador de tiempo parcial**  
**Ama de casa**  
**Jubilado/a**  
**Sin trabajo**  
**Estudiante**  
**Otro**

**Lo que soy yo generalmente? Jubilado.**

**Si responde "Otro"**

**52a. ¿Cómo describiría su situación laboral?**

**Si responde "Trabajador"**

**52b. ¿Cuál es su trabajo actual?**

**Bueno, mi trabajo donde estaba trabajando era la city Miami," ba".**

**Si responde "Sin trabajo" o "Jubilado/a"**

**52c. ¿Cuál era su trabajo?**

**Bueno haciendo de libre.**

**Si está casado/a**

**52d. ¿Cuál es el trabajo de su esposo/a?**

**SI EL ESPOSO/LA ESPOSA ESTA SIN TRABAJO O JUBILADO/A:**

**(52d)1**

**¿Cuál era el trabajo de su esposo/a?**

**53. ¿Cuál es su nivel educativo? ¿Cuál fue el último curso que terminó en la escuela, o el último año que cursó? Octavo grado.**

(ENTREVISTADOR: MARQUE CON UN CIRCULO O ESCRIBA LA RESPUESTA)

0    1    2    3    4    5    6    7    8    9    10    11  
12   13   14   15   16   M.A./M.S.

OTRO:

54. ¿Tiene hijos? *Sí, uno.*

*Si responde Sí:* 54a. ¿Cuántos viven con usted? *Ninguno.*

54b. ¿Cuántos años tienen? *SI SOLO TIENE UNO: ¿Cuántos años tiene? Sesenta y seis.*

55. Voy a leer una lista de personas, cuando termine dígame las personas de esta lista que viven con usted.

Usted vive con: su esposo o esposa, su novio o su novia, sus padres o sus suegros, vive solo, vive con otras personas que no están en esta lista . *Vive solo, vive solo. Yá.*

*Si responde "Con otras personas":* 55a. ¿Puede decirme quién vive con usted?

56. Incluyéndole a usted, ¿cuántas personas viven en su casa? *Ninguna.*

57. Según la siguiente lista, ¿puede decirme su origen étnico o racial?

Blanco, no hispano

Afro-americano o negro, no hispano

Asiático o de las islas del Pacífico

Nativo americano

Hispano, independientemente de la raza

*Bueno, yo no se como puedo ponerle ahí, si es hispano, o blanco. No se qué quiere decir eso. No se qué quiere decir ? Sí, sí qué pone ahora.*



*Si responde "Hispano": 57a. ¿Puede decirme de qué país o países es originaria su familia?  
Cuba.*

58. *¿Cuáles son los ingresos de su familia?*

*No, no se. Los mois del retiro \$470 pesos de Social security.*

*SI ES NECESARIO, EXPLIQUE: Incluya cuanto dinero ganan usted y su esposo/a.*

*ENTREVISTADOR: EL PACIENTE PUEDE DARLE UN SALARIO ANUAL, MENSUAL,  
SEMANAL O POR HORA.*

*LA CIFRA DADA ES (MARQUE UNO)*

- ☐ ANUAL
- ☐ MENSUAL
- ☐ SEMANAL
- ☐ POR HORA

*Si responde "Por hora", pregunte: 58a. ¿Cuántas horas trabaja cada semana?*

*SI ES NECESARIO, PREGUNTE: 58b. ¿Cuántas horas trabaja su esposo/a por semana?*

**MUCHAS GRACIAS POR SU AYUDA**